



FRAGILE X ASSOCIATION OF AUSTRALIA

STRATEGIC PLAN

2022-2025

30 YEARS STRONG | SUPPORTING | SHARING | CONNECTING | INFORMING

The Fragile X Association of Australia (FXAA) represents people living with Fragile X

People living with Fragile X includes those who live with Fragile X Syndrome or Fragile X premutation and their families.

Fragile X Premutation Associated Conditions (FXPAC) include Fragile-associated Primary Ovarian Insufficiency (FXPOI), Fragile X-associated Tremor Ataxia Syndrome (FXTAS) and a range of various associated conditions.

OUR VISION

- People living with Fragile X are empowered to live their best possible lives

OUR MISSION

- FXAA's mission is to support people living with FX through connection, education and advocacy

OUR ROLE

- Connect people living with Fragile X with the Fragile X community and provide support
- Provide information and education for people living with Fragile X and the Fragile X community
- Influence public policy, advocate for research and build partnerships
- Develop knowledge of Fragile X in health care professionals, educators and service providers

FOCUS AREA 1: SUPPORT AND CONNECTION
Provide support to people living with FX and facilitate connections

	Goal 1.1 Support the wellbeing of individuals and families	Goal 1.2 Facilitate peer support and connections	Goal 1.3 Facilitate access to services and supports
Strategies	a. Deliver individual and family counselling in-person and remotely	a. Facilitate group, cohort or interest-based connections and meet-ups	a. Provide referrals and facilitate access to services
		b. Facilitate social media peer support and connection	b. Provide information via Helpline
		c. Share individual and family stories	c. Facilitate access to specialist Fragile X clinics

FOCUS AREA 2: EMPOWERMENT

Provide information and education for people living with Fragile X

	Goal 2.1 Increase understanding and knowledge of Fragile X conditions and their impacts	Goal 2.2 Increase understanding of interventions, management and research	Goal 2.3 Increase knowledge and skills to navigate the NDIS and other services
Strategies	a. Be an information hub on Fragile X “Understanding Fragile X”	a. Be an information hub for individuals and families “Living with Fragile X”.	a. Deliver educational events on the NDIS and other services
	b. Develop and publish information on Fragile X in a range of different formats and for different audiences	b. Develop and publish information on Fragile X interventions, management and research	b. Publish and disseminate information on the NDIS and Fragile X
	c. Deliver educational events with experts on Fragile X conditions and their impacts	c. Deliver educational events with experts on interventions, management, treatments and research	c. Facilitate peer support in relation to NDIS and other services

FOCUS AREA 3: ADVOCACY

Be a strong voice for Fragile X, influence public policy and advocate for research

	Goal 3.1 Increase awareness of Fragile X with government, professionals and the broader community	Goal 3.2 Effect public policy change and advocate for improvements in testing, screening, diagnosis, management and supports	Goal 3.3 Promote research and facilitate opportunities for engagement
Strategies	a. Disseminate Fragile X information at health and disability forums and events	a. Advocate for public policy change in areas impacting the FX community including in the NDIS	a. Communicate information on developments in research, testing and treatments
	b. Raise awareness of Fragile X via increased visibility of Fragile X in social and mainstream media	b. Be a strong voice for the Fragile X community in health and disability forums	b. Build partnerships with researchers and international bodies
	c. Stimulate increased engagement of professionals in Fragile X	c. Build partnerships with advocacy and representative organisations in the health and disability sectors	c. Advocate for Fragile X community engagement in research and clinical studies
		d. Advocate for enhanced Fragile X testing and screening to promote early diagnosis of Fragile X full mutation and premutation	d. Build and map knowledge about the Fragile X community in Australia

FOCUS AREA 4: EDUCATION FOR PROFESSIONALS
Educate health professionals, educators and service providers

	Goal 4.1 Increase Fragile X knowledge and expertise in health professionals	Goal 4.2 Increase educators' understanding of Fragile X and learning	Goal 4.3 Increase service providers' understanding of Fragile X
Strategies	a. Provide information, support and referrals for medical and allied health professionals through a “Health Professionals Hub” and the Helpline	a. Provide information, support and referrals for educators, including early childhood, primary, secondary, special and vocational educators and support staff through an “Educator Hub” and the Helpline	a. Provide information, support and referrals for service providers, including adult support services, NDIS providers, support workers, accommodation providers, employers, recreation service providers and NDIS planners through a “Service Provider Hub” and the Helpline
	b. Develop and facilitate delivery of training and education for health professionals and student professionals	b. Deliver training and education for educators	b. Deliver training and education for service providers
	c. Drive the establishment and facilitate the continuation of clinical services delivering Fragile X specialist services		

